



# Connecting Families the P2P Way!

Presented at AMCHP, Washington D.C.

February 10, 2013

by

Kathy Brill, Executive Director, P2P USA and  
Joni Bruce, Executive Director, Oklahoma Family Network

# Parent to Parent Basics



- Parent to parent support, promoted by Parent to Parent USA, is the intentional matching of an experienced, prepared, Support Parent with a parent seeking peer support.
- Parent to Parent USA Alliance Members are statewide organizations providing support and information to families with children who have special health care needs or disabilities, most notably through parent to parent support.

# Parent to Parent Support



- *“When you come to a place where the streets are not marked”* Dr. Suess

Parent to Parent support can be a life-line, knowing there is an experienced guide, a trusted ally, a listening partner just a phone call away.

# Parent to Parent Movement



- Grassroots effort began in Omaha Arc, Nebraska early 1970s.
  - Fran Porter, Shirley Dean and Patty McGill Smith
  - Nebraska, Iowa, Kansas, Missouri
  - 1974 Parents Helping Parents, CA
  - 1975 Education Act P.L. 94-142
  - 1976 Parent Training and Information Centers
  - 1979 Pilot Parents of AZ
  - 1980 Washington State Parent to Parent

# P2P Today



- 2006 Parent to Parent USA Non-profit Status (until 2002, TA support received through Beach Center on Families with Disabilities)
- 2012 Opened office in DC, hired first ED
- 32 Alliance Members
- 3 Emerging Alliance Members
- 32,007 families matched nationally in 2011

# Quality Standards from Research

- Qualitative Research proves P2P Efficacy
- Quality Standards created by P2P USA based on research
- All Alliance Members MUST follow quality standards to maintain membership

# Research Results

- Families felt less isolated and more confident in their ability to care for their child and more hopeful about their future
- Parent to parent was helpful for a majority of parents from diverse backgrounds and across all income levels
- Parents who participated made significantly more progress in getting their needs met compared to parents in the “wait group”.

# Research Results



- Parent to Parent support increases parents' adaptation to their situation
- Helps parents better manage their day-to-day lives and helps parents find answers to their questions
- 89% of parents in the study found Parent to Parent support to be helpful (hence development of quality standards)



# Parent to Parent Program



- Evidence-Based Practice
  - Program maintains the capacity to match families with diverse experiences including but not limited to ethnicity, culture, race, language, socio-economic, disability, special health need, and other child/family related factors
  - Program participates in continuous quality improvement efforts

# The Match

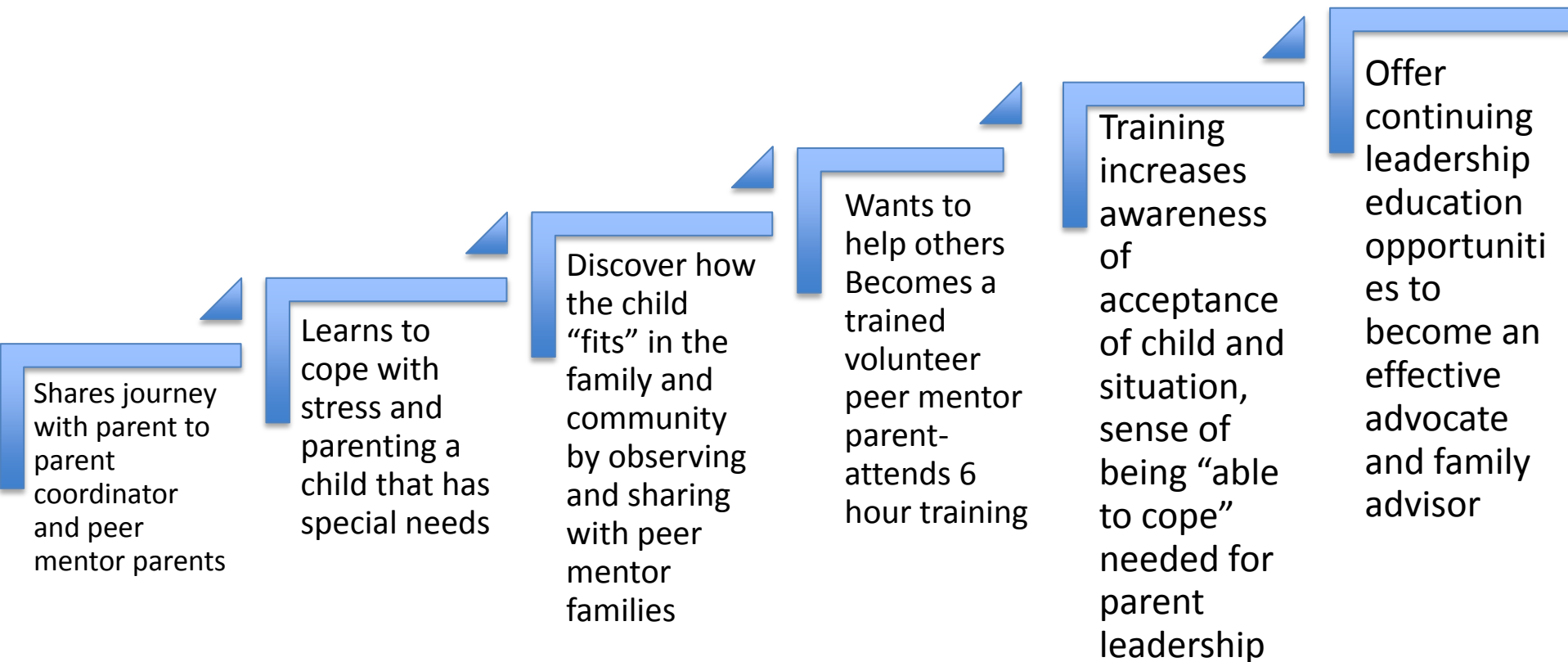


- Evidence-Based Practice
  - Criteria for the match are driven by the concerns, needs and priorities of the Referred Parent
  - Matches are made within 24-48 hours of request with a trained Support Parent
  - Support Parent makes at least 4 contact with the first 8 weeks of receiving the match
  - All matches are followed-up by program to ensure match was a success; rematch if needed

# Parent to Parent Program Implications

- Perceived sameness is a fundamental ingredient for success in a Parent to Parent match.
- There is a strong relationship between the number of contacts a parent has with a Support Parent and how helpful the parent finds Parent to Parent support to be.

# From Parent Support to Parent Leadership: The Cradle of Leadership



# To Become Alliance Member

- P2P support is core program component
- Must serve families statewide, across disability/special health care needs, across all ages
- Committed to implementing evidence-based practices for...
  - P2P Support, Recruiting & Training Support Parents, and Matching & Follow-up
- P2P USA survey completed annually

# What do P2P USA Alliance Members get in return?

- Technical Assistance
- Use of P2P Directors' National Listserv
- Use of National Matching Listserv
- Invitation to Biennial Directors' Leadership Institute
- Forum for leadership, networking, problem-solving nationally
- National exposure, connections, forum for family support issues, etc.

# If you want to connect or collaborate with an existing P2P Alliance Member

1. Go to [www.p2pusa.org](http://www.p2pusa.org)
2. Click on “Looking for Support”
3. On the US map, click on your state for all contact information

Or...contact Kathy Brill at (717) 503-8992 or [kathyb@p2pusa.org](mailto:kathyb@p2pusa.org) to further discuss your needs and plans

# QUESTIONS?



***Additional information about Parent to Parent  
can be found on website at [www.p2pusa.org](http://www.p2pusa.org)***

Thanks!





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# Engaging Family Leaders to Address State and National Performance Objectives

## Kayzy Bigler

Parent Information Specialist  
Families Together, Inc.



## Donna Yadrich, MPA, CCRP

Kansas CYSHCN Family Advisory Council  
AMCHP Family Scholar

## Heather Smith, MPH

CYSHCN Health Planning Consultant  
Kansas Department of Health and Environment

# MCH = Family Engagement

**Children and Youth with  
Special Health Care Needs  
(CYSHCN) Program**

+

**Family-to-Family Health  
Information Center (F2F-HIC)**

=

**Strong Collaboration to  
Engage Families**



# Foundation of the FAC



# Foundation of the FAC

## FAC MISSION

To achieve satisfaction of special health care services for families of CYSHCN by advising and promoting opportunities for individuals with health care needs or disabilities to exercise self-determination.

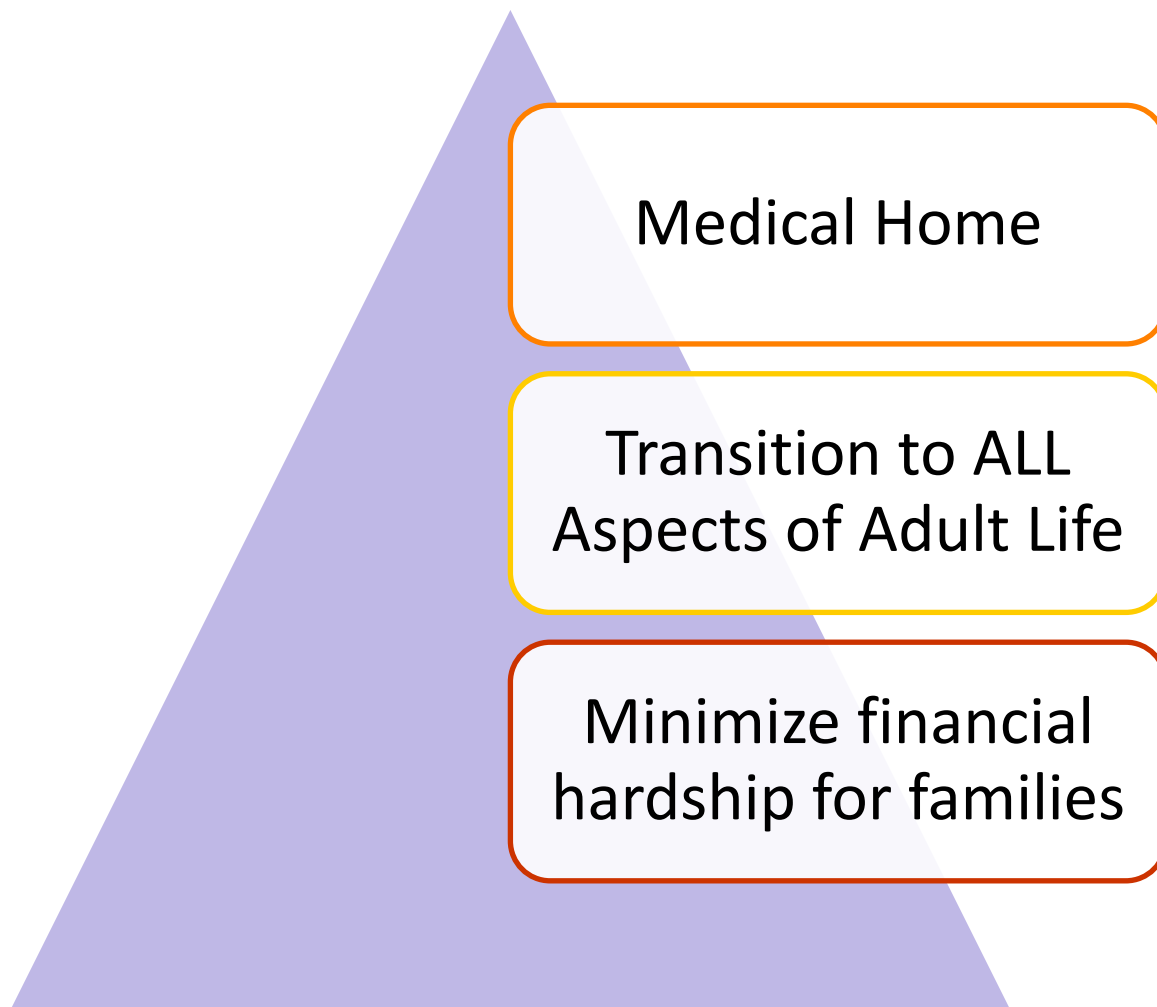
## FAC VISION

“Families of CYSHCN are partners in decision-making at all levels and are satisfied with the services they receive.”

*~MCH Core Performance Measure #1*



# State-Level MCH Priorities





# The Glue the Holds Us Together

## *The FAC Bylaws*

- ❑ **Approved** by Members
- ❑ Outlines the FAC **Structure**
  - Mission & Vision
  - Roles & Responsibilities
  - Membership
  - Executive Committee
  - Logistical & Operational Components
- ❑ **Changes** WITH the Group



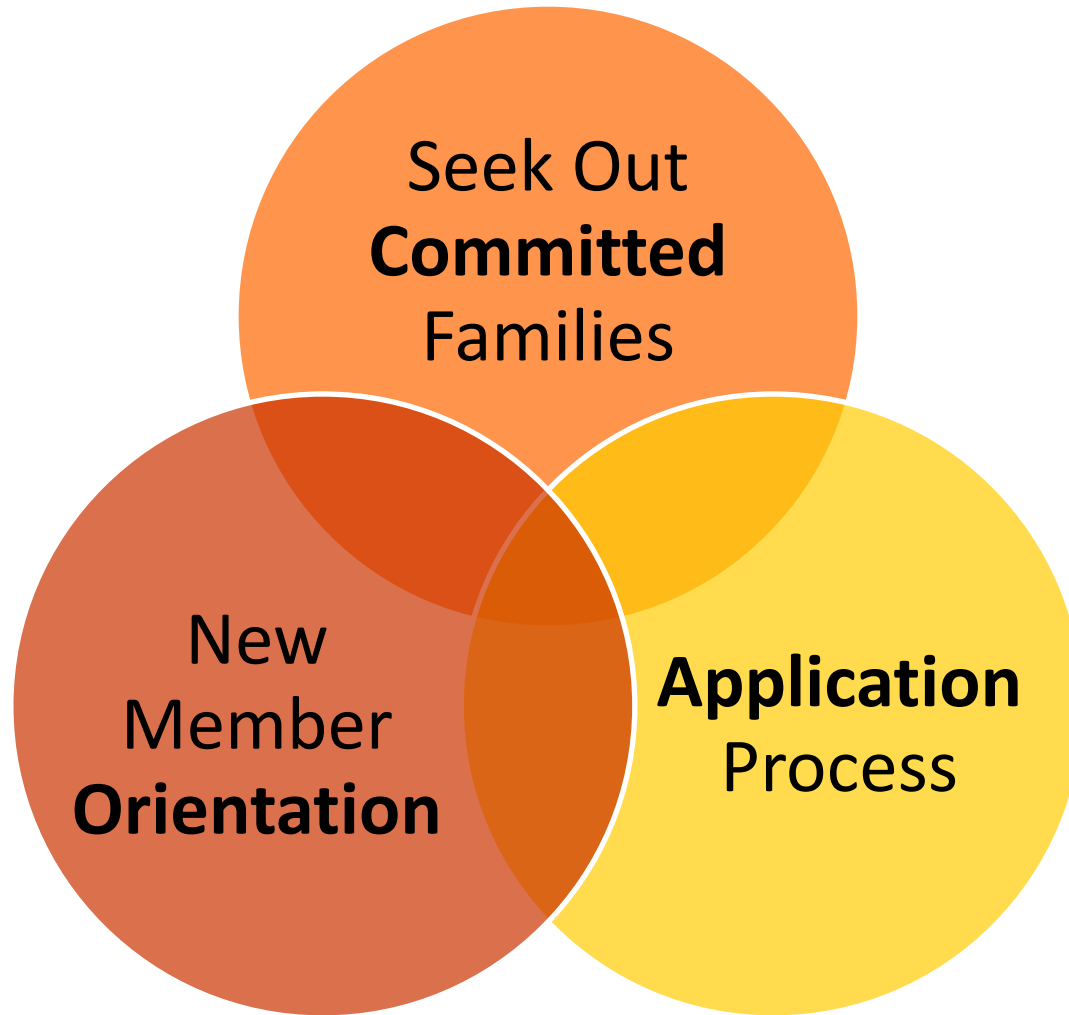
# Role of the FAC

- ❑ CYSHCN Program **Consultants**
  - State & National Priorities
  - Resource to CYSHCN Program
  - Identify Needs of KS Families
- ❑ **Advocate** for CYSHCN and Family Needs
  - Ambassadors to Local Communities
  - Relay Needs to Service Providers
  - Build Awareness
- ❑ Develop & **Share Resources**
  - Participate in Work Groups or Projects





# The Key is Recruitment



# FAC Membership

**Title V**

**Families**

**F2F-HIC**

- Regional Representation
- Culturally Diverse
- Various Family/Child Needs
- Broad Definition of CYSHCN and Disability
- Individual and Unique Experiences



**Leadership**  
**Quality &**  
**Action**

# FAC Logistics

- ❑ Membership = 9 – 15 **Family Members**
  - 2 year commitment
- ❑ Quarterly **In-Person** Meetings x 4
  - Locations rotate across the state
  - Interim Conference Calls
- ❑ Family **Compensation**
  - Stipends, Mileage, Child Care, etc.
- ❑ **Executive** Committee



# FAC Projects or Work Groups

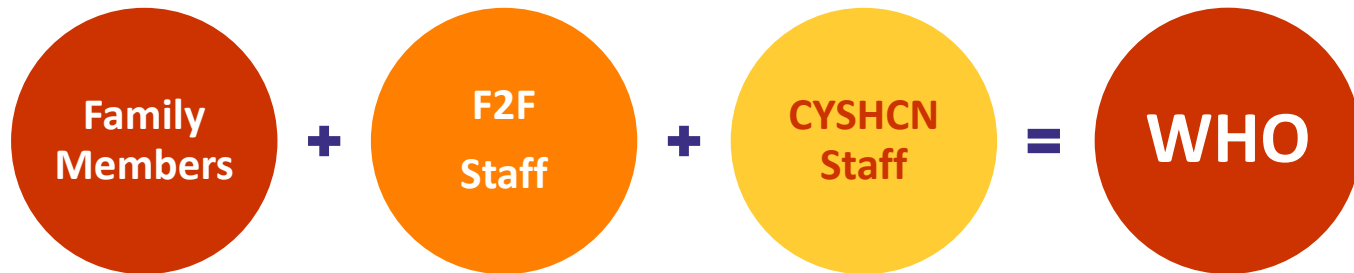
- ❑ **Active Participation** in Meetings & Projects
- ❑ Focus is Always on State & National **CYSHCN Objectives**
- ❑ FAC Projects are **Chosen by Members**



- ❑ Current Project Determines **Work Group Structure**
  - Small Groups vs. Large Group



# We've shared the who...



# ...and the why...



# ...it's time for the what, when, and how!!



## What

- Community Resource Brochure
- Medical Home Rack Card
- Transition Booklets
- Impact Paper

## When

- Began – March 2011
- Products Completed March 2012
- Paper Completed December 2012

## How

- Work Groups
- Team Work



# Medical Home Rack Card

# Community Resource Brochure

*Families Make the Difference!*

## HOW TO BUILD MEDICAL PARTNERSHIPS!

As a parent, partnership with your child's health care providers is the key to quality care!

When parents and their child/youth team up with healthcare providers, the child receives the highest quality care in the most efficient manner.



This concept of partnership between patients, families and the child's primary care physician forms a **Medical Home**.

Health care and community components of the **Medical Home** depend on the patient and family needs. Work with your doctor to determine which components best fit your family's current and changing needs.



For more information, visit [www.familiesstogetherinc.org](http://www.familiesstogetherinc.org) or call the center nearest you:


Topeka	1.800.264.6343 or 785.233.4777
Garden City	1.888.525.6364 or 620.276.6364
Wichita	1.888.815.6364 or 316.946.7747
Kansas City	1.877.499.5369 or 913.287.1970
Spanish	1.800.450.9443

 Families Together, Inc., Parent Training and Information and Family-to-Family Health Centers for Kansas, assisting parents and their sons and daughters with disabilities and special health care needs.



## Kansas Guide to Health and Community Resources

Helping families navigate services and resources for their children and youth with special health care needs.



This brochure can get you started on finding the following resources:

- Health Insurance Options
- Specialty Care
- Assistive Technology
- Advocacy
- Family & Peer Supports
- ...and more



# Transition Readiness Booklet Series

## The Future Is Now THINK BIG!!!

Taking the FIRST  
Steps Towards  
Helping Your Child  
be Independent



PREPARING FOR TRANSITION PLANNING

FOR PARENTS OF CHILDREN AGES 0 – 6 YEARS OLD

## The Future Is Now THINK BIG!!!

Taking Steps  
Towards  
being  
Independent



FOR TRANSITION PLANNING  
Teens and Teenagers 7-13 years old

## The Future Is Now THINK BIG!!!

Taking Steps  
Towards  
Independence



PREPARING FOR TRANSITION PLANNING

For Youth and Young Adults 14-19 years old



# FAC Impact Paper

- Journal for Applied Family Studies – Special Edition on Families and Disabilities



# FAC Impact Paper

## □ Title V & F2F Support

- Developed Work Plan
- Data Collection
- Guided Discussions
- “Editor(s) in Chief”
- Brainstorming Question Worksheets

Hello Everyone,

It is done!!! YEA! We submitted your paper this morning and will now wait patiently for a response. All of you did a wonderful job on this project and should be very proud of yourself. I know that Heather and I are proud of each one of you! We know that this was no easy project to do, but we truly believe it will be worth the time, effort and emotion you put into it. We will keep you posted on the progress as we hear. Thanks and Have a happy holiday!

--

Kayzy Bigler  
Families Together, Inc. Parent-to-Parent Coordinator

**Collective Cheer!!!!**

Finally submitted! 😊

# Evaluate & Re-Evaluate!

## What Worked?

- Project Opportunities
- Support and Resources

- ❑ Staff share new project ideas as they become available
- ❑ Staff provide TA and support as needed

## What Didn't?

- Weekday meetings
- Lack of structure or accountability

- ❑ Meetings moved to Saturdays
- ❑ Developed new member orientation process
- ❑ Initiated the Executive Committee



# 2012 FAC Survey Results

*percentage = always to almost always*

86%

- Projects & activities have a **POSITIVE** impact on KS families

100%

- **SATISFIED** with guidance from KDHE and Families Together

100%

- Involvement is **BENEFICIAL**

100%

- Involvement has **IMPROVED ADVOCACY** skills

100%

- FAC effectively **ADDRESSES ISSUES** for CYSHCN

Leadership  
Quality &  
Action

# FAC Survey Comments

*“With the drastic budget cuts and program realignments, family voices are vital to salvage the health and well-being of our children and youth.”*

*“I feel the FAC is a wonderful way to get a whole picture of what is needed for CYSHCN.”*

*“We have great leadership. One person can make the world better. Every one of us combined are important and help reach those who have a special need. Every voice counts and is heard.”*



# FAC Value to CYSHCN Program

## *Collective State Gain*

### ❑ State Decision-Makers

- Parent expertise available as consultants
- Deeper understanding of families' daily struggles

### ❑ CYSHCN Program

- Data verification as more “family friendly”
- Evaluations confirm improved CYSHCN services

### ❑ Legislators

- Awareness of the importance of MCH funding



# FAC Value to Families

## ❑ Leadership Development

- Lead by Example

## ❑ Build Advocacy Skills

- Advocate for Funds
- Advocate for Services
- Advocate for Family/Patient Rights

## ❑ Peer Support

- Enough said...



# How Has the FAC Engaged You as a Family Leader?

## ❑ Debbie

- “I have been able to educate people everywhere I go about us...It takes team work to help us get the resources out to those who need them and don't know they are out there.”
- “I am so thankful and am proud to be a part of the FAC.”





# How Has the FAC Engaged You as a Family Leader?

## □ Joe

- “In spite of the constraints, the breakthroughs, the setbacks, the joys, the sacrifice, and the successes of being a parent of a child with special needs, being a member of the Family Advisory Council has been elevating.”
- “I feel that whatever I may have experienced in the past my efforts could help a family in the future be a little wiser or have their task be a little lighter or more expedient.”



# How Has the FAC Engaged You as a Family Leader?

## ❑ Deanna

- “Being part of FAC has helped me as a family leader by knowing I am not the only one fighting this daily battle of getting what my child needs to lead a normal and productive life...Having our FAC has given me the courage and determination to help others fulfill their dreams for their children.”



# FAC Membership: It's Personal



- ☐ Advocacy
- ☐ Leadership Skills
- ☐ Support from Others
- ☐ Giving Back

**Recycling Got Me Here!!!**

*Powered by AudreySpirit*

*Audrey Grace Yadrich*



# Questions?

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Leadership  
Quality &  
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